Active Tuberculosis Disease

Information for patients and families

Read this information to learn:

• What active tuberculosis disease is
• How to treat it
• About the TB clinic
• Who to contact if you have any questions

What is Tuberculosis (TB)?
Tuberculosis (TB) is a bacterial infection caused by a tiny germ called “Mycobacterium tuberculosis”. TB can affect any part of the body but usually affects the lungs.

If a person who has Active TB Disease in their lungs, coughs, sneezes or shouts, the TB bacteria (germs) spray into the air. Another person may breathe the bacteria into his/ her lungs. Most people who breathe in the TB bacteria are able to stop it from growing because their body’s immune system controls it. The bacteria remain alive but not growing. This is called inactive or Latent TB Infection (LTBI).
People with Latent TB Infection are not sick and cannot spread TB to others. Some people, who are otherwise healthy, (about 10%) with LTBI may go on to develop Active TB Disease if their immune system cannot stop the TB bacteria from growing. A person with Active TB Disease often feels sick and may infect others.

**TB can be cured with antibiotic medications.**

How contagious is TB?
TB is not as contagious as the flu or chickenpox. A person must spend many hours every day in close contact with a person with active TB disease in their lungs. People cannot get infected with TB by physical or sexual contact (handshakes, sitting on toilet seats or sharing dishes with someone who has TB.)

Some people are at higher risk of having TB:

- People who have had close and long contact with people who have active TB of the lungs or throat
- People from areas of the world where TB is common
- People with alcohol use disorder
- People who are injection drug users
- People experiencing homelessness
- Staff and residents of nursing homes, shelters, hospitals and jails
- Elderly people, especially those who have lived at a time when TB was common
Progression of Latent TB infection to Active TB disease

Why does Latent TB infection develop to Active TB disease?
A person with TB infection may develop TB disease if their immune system can’t stop the bacteria from growing. The highest risk of TB disease is within the first 2 years of becoming infected. After the first 2 years, there is about a 5% to 10% chance of developing TB disease in an otherwise healthy person’s lifetime. This often happens when their immune system weakens.

Once infected, who is more likely to get TB disease?
People with weakened immune systems are even more likely to get TB disease. Babies, preschool children and the elderly have weaker immune systems than healthy adults.

The following conditions also weaken the immune system:

- Organ transplants
- Silicosis
- Diabetes
- Low body weight
- Steroid medications
- HIV infection
- Kidney disease
- Cancer
- Abuse of alcohol or drugs
Active TB disease

What is Active TB disease?
A person with active TB disease has been exposed to the TB bacteria and their immune system is unable to stop the bacteria from growing. Someone with TB disease feels sick and may spread TB to others. It is a legal requirement that you must take the prescribed medicine for your own health and to prevent the spread of TB to other people.

What are the symptoms of TB disease?
Symptoms depend on where the TB bacteria are growing in the body.

TB in the lungs may cause the following:

• A cough that lasts longer than 3 weeks
• Coughing up blood or sputum (phlegm)
• Weakness or feeling very tired
• Weight loss
• Chills
• Night sweats
• No appetite
• Fever

People with Active Pulmonary TB can spread the infection to others by coughing or sneezing the bacteria into the air. To stop the spread of the TB bacteria they may have to wear masks. Your doctor and public health department will determine the safety precautions that must be taken. Doctors and nurses wear masks when caring for these patients.
**TB outside the lungs:**
The TB germ spreads through the blood to other parts of the body and TB can develop anywhere outside the lungs. Symptoms will depend on where in the body the TB is growing.

For example

- **Lymph nodes:** lumps in the neck
- **Kidneys:** very few symptoms
- **Bones and joints:** pain in the bones or back, and redness or swelling
- **Gut:** stomach pain and change in bowel movements
- **Brain and spinal cord:** headaches, stiff neck, paralysis

People with TB disease outside the lungs may also feel tired and have weight loss, fever and night sweats. They usually cannot infect others. The TB bacteria don't usually get into the air to be breathed in by someone else. These people usually don’t need to take any precautions to stop the spread of TB.

**How is TB diagnosed?**
Your doctor will examine you and may order tests such as:

- **TB skin test:** TB proteins are injected under the surface of the skin. If a person is infected with TB a hard swelling (induration) will appear at the site.

- **Chest x-ray:** looks for signs of TB disease in the lungs

- **CT scan:** a special x-ray that takes detailed pictures of the body.

- **Biopsy:** a sample of tissue is removed from the affected area of the body to look for TB germs.

- **Sputum Induction:** a mist treatment that stimulates coughing, to obtain a sputum (phlegm) sample.
**What is a TB skin test?**

A TB skin test is used to diagnose TB infection. TB proteins are injected under the surface of the skin. If a person is infected with TB, a hard swelling (induration) will develop at the site of the injection in 48 to 72 hours. A doctor or nurse must interpret all TB Skin Tests. They will take the size of the reaction, your medical history and risk factors into consideration.

Sometimes people receive a TB Vaccine called BCG. If you have had BCG and have risk factors for TB Infection, the vaccine will not affect the interpretation of your TB Skin Test.

**What is sputum induction?**

Obtaining sputum (phlegm) samples for testing is important in the diagnosis of TB disease in the lungs. In most TB clinics, patients who cannot give samples must have a bronchoscopy. Since this procedure is uncomfortable for patients, the Toronto Western Hospital TB Clinic has developed a Sputum Induction Booth. Here, sputum samples can be safely obtained in a more comfortable manner.

The Sputum Induction Booth is a clear Plexiglas booth. The booth’s special air filtration unit has filters, which clean the air and vent it outside the building to protect you and the TB Clinic staff.

During the procedure you sit comfortably in the booth and breathe in a salty mist through a mask. A Respiratory Therapist, who will stay with you during the test, will give this to you. The salty mist loosens the phlegm in the lungs and makes you cough. Samples can be taken of the phlegm.

The time required for sputum induction varies, but is usually completed within 30 to 60 minutes. Sputum samples are then sent to the Ontario Ministry of Health Lab for testing.
Why is TB and HIV infection dangerous?
HIV is a virus that weakens the immune system. People who have TB and HIV infection are at a very high risk of TB infection progressing to TB disease. People with HIV infection are more likely to develop TB and the TB symptoms may not be typical, delaying the diagnosis and the treatment of TB disease.

Everyone with HIV should be tested for TB and everyone with TB should be tested for HIV. You may be asked to have an HIV test.

What is contact tracing?
If you have TB disease in your lungs, you may spread TB to others. It is the law that the TB Clinic reports all cases of TB to the Public Health department.

A Public Health Nurse will help you with your treatment and find contacts (people you spend a lot of time with). This is called contact tracing. People who are contacts should have a TB skin test to look for TB infection. This is very important to stop the spread of TB.

Treatment of Tuberculosis
The TB germ is very strong and you will need to take a number of antibiotic medications for 6 months or longer depending on the type of TB you have. You must take all your pills every day even if you feel better.

The usual TB treatment includes the following medications:

• Isoniazid (INH)
• Rifampin (RMP)
• Pyrazinamide (PZA)
• Ethambutol (EMB)
• Pyridoxine (Vitamin B6)

TB medications are free to you and will be provided by the TB clinic. During your TB treatment you must be seen at the clinic every month for check-ups, blood tests and refills of your pills.
How to take your medication:

• Store your pills at room temperature in a dry place, away from children.

• Take your medication on an empty stomach. If this causes an upset stomach, you may take the medication with meals.

• Take your medication at the same time every day to help you remember (for example, before breakfast).

• Do not drink alcohol (such as beer, wine, alcoholic drinks) while taking TB medications.

• Avoid antacids that contain aluminum.

• If you forget to take your medication one day just continue taking your next dose as usual. **Do not double the dose.**

Possible side effects of TB treatment:
Most people have no problems while taking TB medications, but if you notice any changes in your health while taking your pills, **call the TB Clinic:**

• skin rash, itching

• yellowish skin or eyes

• loss of appetite

• swollen or painful joints

• stomach cramps

• flu-like symptoms (fever, chills, dizziness, shortness of breath)

• pain, numbness or tingling in your fingers or toes

• blurred vision or changes in how you see colour

• nausea, vomiting, upset stomach

• very dark urine

• fatigue (feeling very tired)

• fever for 3 days or more
If you have any of these serious side effects stop taking your pills and call the TB Clinic Nurse Practitioner immediately at 416 603 5395 OR the TB Clinic Nurse Clinician at 416 603 5800 ext. 3844.

If you have any serious side effects during holidays or weekends, go to the Emergency department at The Toronto Western Hospital.

What if I don’t take all my medication?
You will probably start to feel better after only a few weeks of treatment. However, you must keep taking the drugs because the TB bacteria are still alive in your body.

If you stop taking your medicine, or don’t take it regularly, drug-resistant TB may develop. You will get sick all over again, but this time you will need to take stronger drugs for a longer time and may have to stay in the hospital.

What is DOT?
DOT or Directly Observed Therapy is a program developed to help you take your drugs regularly. If you are on a DOT program, you will meet with a health care worker every day or several times a week. DOT helps in many ways.

You will be reminded to take your medicine and complete your treatment. The health care worker can also make sure the antibiotics are working as they should, watch for side effects, and answer questions you may have about TB.
TB Medications

Isoniazid (INH)

Tips for taking this medicine:

• Take this medicine on an empty stomach. If it upsets your stomach, take it after meals.

Why might I need to take Vitamin B6 (Pyridoxine) at the same time?
Vitamin B will help to prevent numbness and tingling in your fingers and toes that can be caused by the INH. You may not need to take this vitamin if you are able to get enough as part of a healthy diet.

Ethambutol (EMB):

Tips for taking this medicine:

• Take this medicine on an empty stomach. If it upsets your stomach, take it after meals.

• If you are pregnant or breast-feeding, tell your doctor before taking this medicine.

• If you take this medicine for a long period of time, you will need to have your eyes checked. EMB can give you blurred vision or change the way you see colours.

Pyrazinamide (PZA):

Tips for taking this medicine:

• Take this medicine on an empty stomach. If it upsets your stomach, take it after meals.

• If you are pregnant or breast-feeding tell your doctor before taking this medicine.

• PZA will make you more sensitive to the sun. Take extra care to protect yourself from the sun.
Rifampin:
Tips for taking this medicine:

• Take this medicine on an empty stomach. If it upsets your stomach, take it after meals.

• Birth control pills will not work while taking this medicine. Use an alternate form of birth control. Please speak to the clinic staff, your family doctor or public health about alternative methods.

• If you are pregnant or breast-feeding talk to your doctor before taking Rifampin.

• Do not wear soft contact lens while taking Rifampin. Dyes in the drug will permanently stain the lenses.

• Rifampin will cause orange or red coloured saliva, tears, urine, and stool. This is not harmful and will stop at the end of treatment.

Visiting the TB Clinic

What do I have to bring with me to clinic appointments?

• All of your medicines (you must bring these with you every time)

• Ontario health card (OHIP)

• Interim Federal Health Papers (if you are a refugee)
What should I expect at a TB Clinic appointment?
The Toronto Western Hospital TB Team tries to make the clinic environment as comfortable and relaxing as possible. You will be checked in at the clinic reception desk, where you may notice staff wearing masks to protect themselves against the TB germ.

Please give the receptionist your OHIP card. You will then be escorted to a clinic room, where a clinic team member will see you. If you need blood work or x-rays, these tests will be done at the hospital.

What if I cannot come to my appointment?
Call the TB Clinic at 416 603 5853 as soon as possible to let the clinic know and to rebook your appointment. It is very important for your health and TB treatment to keep regular clinic appointments.

What happens if I don’t come for my scheduled appointment?
If you do not come to your appointment and have not cancelled it, the clinic will send a letter to your home, advising you about the missed appointment and asking you to book another one as soon as possible.

What if I need an interpreter?
The TB Clinic may be able provide an interpreter for you. Please call the TB Clinic in advance to ask for this service. You can bring a family member or friend with you.
The Toronto Western Hospital TB Clinic Team

The Toronto Western Hospital Tuberculosis Clinic has a variety of staff to help you through your TB treatment.

• The TB Clinic Doctors specialize in the treatment of TB and have many years of experience.

• The TB Clinic Nurse Practitioner and Nurse Clinician have special training in the treatment of TB and will be your main contact with the TB Clinic. Please call them if you have any problems with your medication, questions or concerns.

• The Public Health Nurse Liaison provides education about the role of the Public Health Department in the treatment and control of TB. They will explain contact tracing, follow-up procedures and DOT programs.

• The Social Worker provides support to TB Clinic patients, families and significant others. They will help you understand the illness and help you adjust to treatment, as well as explain the myths and misconceptions about TB. The Social Worker can also link you with community resources and services such as welfare, shelters, legal and immigration matters.

• The Respiratory Therapists are specially trained to perform the sputum induction procedure and operate the sputum induction booth. They provide education and support during this procedure and may also provide care during your visits to the clinic.
Other resources

Where can I get more information about TB?

Toronto Public Health Department, TB Prevention Team
Phone:  416 392 7457
Email: targettb@toronto.ca

Health Canada Tuberculosis, Prevention and Control
Website:  www.hc-sc.gc.ca/hc-ps/dc-ma/tuberculosis-eng.php

The Lung Association
Website:  www.lung.ca

Stop Tuberculosis Canada
Website:  https://stoptbcanada.org

Centers for Disease Control, Division of Tuberculosis Elimination
Website:  www.cdc.gov/tb

Rutgers New Jersey Medical School, Global Tuberculosis Institute
Website:  http://globaltb.njms.rutgers.edu/

International Union Against Tuberculosis and Lung Disease
Website:  www.theunion.org
Contacts

Clinic hours
Monday, Tuesday and Thursday
8:30 am to 12 noon

Location
Toronto Western Hospital
East Wing – 8th Floor
399 Bathurst St., Toronto, Ontario, M5T 2S8

Appointment booking
Phone: 416 603 5853
Fax: 416 603 5987

Call for problems with medication, side effects, questions or concerns:
Nurse Practitioner: Judith Lang
Phone: 416 603 5395

Nurse Clinician: Andrea Moore
Phone: 416 603 5800 ext. 3844
Fax: 416 603 5987

Monday to Friday 8:00 am to 4:00 pm

For problems with side effects during the weekend or holidays
go to the Toronto Western Hospital Emergency Department at
399 Bathurst St.

Visit www.uhnpatienteducation.ca for more health information. Contact us to provide feedback or request this brochure in a different format, such as large print or electronic formats: pfep@uhn.ca